

Letter to the Editor

Problem of Offering Unsolicited Clinical Genetic Advice and Diagnoses to Nonmedical Friends and Strangers

To the Editor:

Robert W. Marion [1996] bravely reports the resistance he encountered and the fractured friendship that resulted when unsolicited, he reported to friends his concerns about Bardet-Biedel syndrome and its implications in their daughter.

Although there may be no one best answer, the simplest and often the best route for any clinician faced with this or a similar dilemma is to work through the health provider, in this case an unnamed pediatrician. Understandably, Marion who was at a resort away from their home when he first observed the girl, felt he could communicate directly and immediately with his friends about the issue. But this backfired and only resulted in their resentment and withdrawal. Working through the pediatrician might have been more time-consuming and tedious, but more productive. And even if that individual had, as the father alleged, found nothing wrong with their daughter, Marion, by talking to him, also would have contributed to that provider's education and thus to the welfare of other patients in that practice.

It is, of course, easy for me to be wise after the event and offer advice (also unsolicited!). Certainly, in view of the father's hostile attitude of denial, perhaps not even the pediatrician could have been effective in changing the family's approach to the child, and only time could have led the man to face the facts. I appreciate Marion's candor in discussing openly this unfortunate episode

about unsolicited communication of diagnostic impressions or other medical advice. Airing his concerns has I suspected been useful for all of us uncertain about how to do "the right thing."

I have gone through similar dilemmas in deciding how to inform a new friend that she almost certainly had Marfan syndrome and some of the implications. I wrote her a letter outlining what I suggested she do. She wrote back, but only after many months, to thank me. But I suspected from her note that it would have been better to have been in direct communication with her or to try to work through her health provider, whose identity, however, I did not know. Whereas the episode ended relatively fortunately—she stopped free lancing, got a job that provided health insurance, and got into a specialized appropriate care setting—nevertheless, I have always wondered just as Marion has, if I could have handled the situation more smoothly.

REFERENCES

Marion RW (1996): Genetic drift: The unsolvable puzzle. *Am J Med Genet* 62:327–329.

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